Connecticut's Guide for Navigating Dementia Care

A Guide for Caregivers and Care Partners

CONNECTICUT

Public Health | Aging and Disability Services

Five Mile Lighthouse,
New Haven, Connecticut

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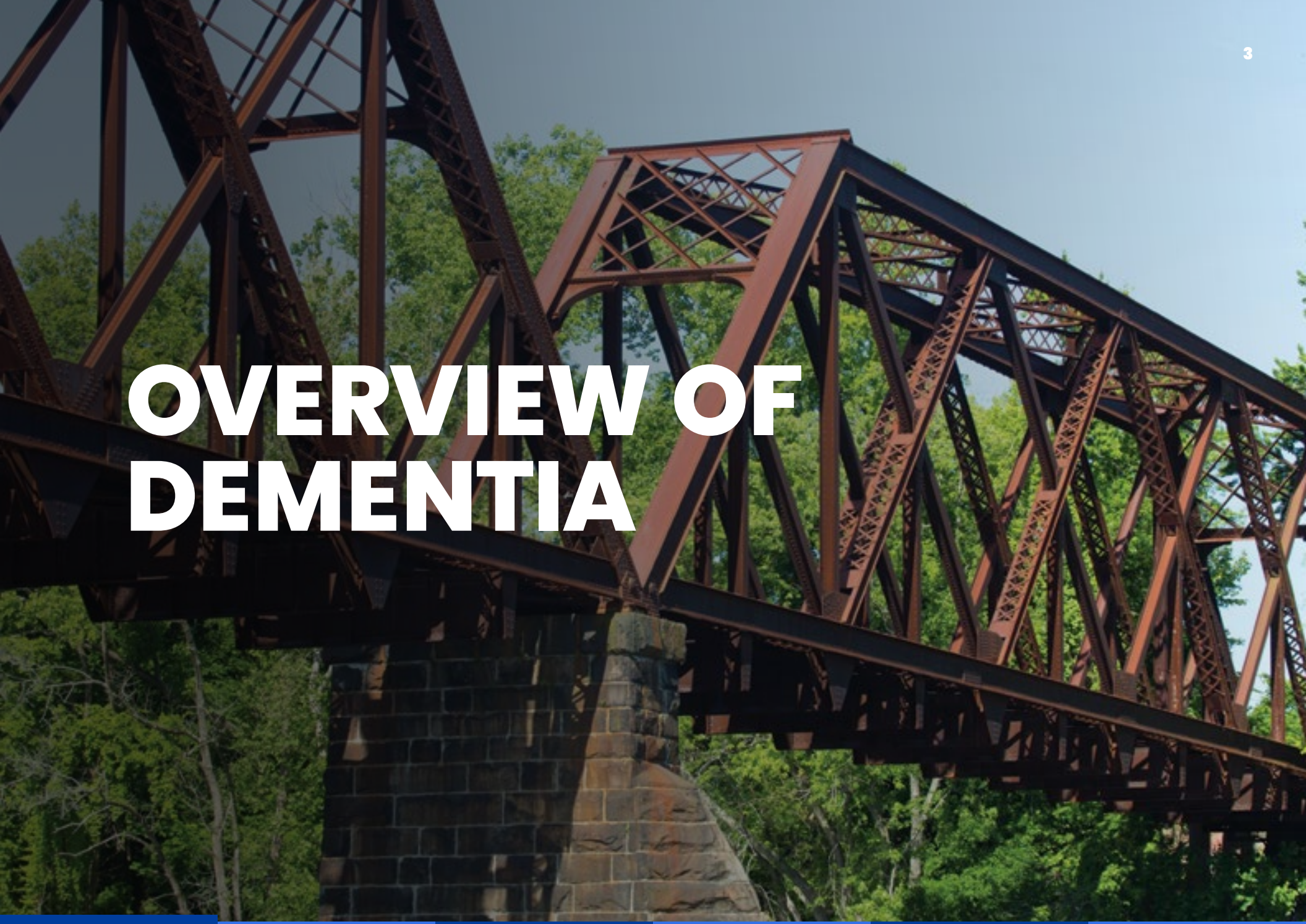


OVERVIEW OF DEMENTIA

OVERVIEW

Are you concerned that someone you care for may be experiencing dementia? If so, this guide can help you learn more about their journey and how to help.

Caring for a person with memory loss or dementia is a process with many twists and turns. The journey of each person living with Alzheimer's disease or other forms of dementia may progress differently, in its own time.

Most friends and families are not prepared and need information, support, and guidance along the way. Consider this your guide for dementia care.

It provides a look at the big picture and the road ahead — and it offers direction about what to expect, what decisions to make, and what steps to take.

If you are a family member, friend, neighbor, or health care worker who supports someone living with **A**lzheimer's **d**isease or **r**elated **d**ementias (**ADRD**), **you are a caregiver**. This Connecticut Guide for Navigating Dementia Care was designed for you – to help you learn the basics about dementia, changes, stages, and tips to help you plan.

Being a caregiver can be overwhelming, but you are not alone. There are many committed Connecticut, and national partners listed at the end of the guide who are ready to assist. Please use this guide and share it widely with others.

There is great hope for people living with ADRD!

Thanks to new medications, treatments, and support becoming available every day, many people are living vibrant, active, meaningful lives with ADRD. As a caregiver, cherish the time you have, take care of your own health, work with your health care team, and remain hopeful for a cure.

The Avery Point Lighthouse
Groton, Connecticut

10 WARNING SIGNS OF DEMENTIA

1. Memory loss that disrupts daily life
2. Challenges in planning or solving problems
3. Difficulty completing tasks at home, at work, or at leisure
4. Confusion with time or place
5. Trouble understanding visual images and spatial relationships
6. New problems with spoken or written words
7. Misplacing things and losing the ability to retrace steps
8. Decreased or poor judgment
9. Withdrawal from work or social activities
10. Changes in mood or personality

QUICK GUIDE FOR NAVIGATING DEMENTIA CARE

For Caregivers and Care Partners. Below are some questions you may be asking at different stages of the dementia journey. Go to the page number next to each stage for more information.

Wondering and worried - *pg 10*

- Is everything OK?
- Should they be checked by a health care professional?
- What if they won't go to a health care professional?

Mild cognitive impairment (MCI) - *pg 13*

- Where do we get their memory loss checked?
- How can I help them with their memory and thinking?
- What can I do to promote their well-being?

Early-stage dementia -*pg 16*

- Are there any medications, treatments, or lifestyle changes that could help their memory and thinking?
- How can I help them stay active and connected?
- Should they still be driving?
- Is their legal paperwork in order?

Mid-stage dementia - *pg 21*

- What can I do to make the home safer?
- What do I do if they won't stop driving?
- Where do I get help in coping with behaviors?
- What services might help and where do I find them?
- How can I make their life more enjoyable?

Late-stage dementia - *pg 27*

- What can I do to promote quality of life?
- What kind of care is best for them?
- What medical care do we want at the end of their life?

Terminology: Caregiver and care partner are used interchangeably to refer to non—professional caregivers, relatives, friends, or community members who support a person living with dementia.

INTRODUCTION

Your Guide for Navigating Dementia Care

In Connecticut, getting help begins with a phone call.

Call your local Area Agency on Aging (AAA) at 800-994-9422.
The AAAs are a trusted resource for information and assistance, where older adults and caregivers can turn to find specialized information, support, and service options in their area: respite programs, in-home care, Medicare counseling, healthy aging programs, and more.
www.agingct.org

Call the Alzheimer's Association at 800-272-3900.
The Association has a 24/7 helpline that provides expert advice, care consultation, and referrals at both national and local levels. Additionally, the helpline can direct callers to local education programs, support groups, and community resources.
www.alz.org/ct

United Way of Connecticut 211
211 is a free, confidential information and referral service that connects people to essential health and human services 24/7/365 online and over the phone. 211's contact specialists can connect you to information about memory care facilities, assistive devices, support groups for caregivers and how to protect yourself from fraud and scams.
Call 2-1-1 or visit www.211ct.org

AGE-RELATED FORGETFULNESS OR SIGNS OF DEMENTIA?

Many people can become more forgetful as they age. Learn the differences between age-related forgetfulness and signs of dementia.

Age-Related Forgetfulness

- Making a bad decision occasionally
- Missing a monthly payment
- Forgetting which day it is and remembering later
- Sometimes forgetting which word to use
- Losing things from time to time

Signs of Dementia

- Making poor judgements and decisions a lot of the time
- Problems taking care of monthly bills
- Losing track of the date or time of year
- Trouble having a conversation
- Misplacing things often and being unable to find them

Talk with a doctor if you notice any changes in memory or thinking that concern you. Learn more

NIH National Institutes of Health
Turning Discovery Into Health

ALZHEIMER'S AND DEMENTIA

What's the difference?

DEMENTIA

Dementia is a general term referring to a loss of cognitive function — remembering, thinking, and reasoning — severe enough to interfere with everyday life. Dementia is not a specific disease, but an overall term describing a wide range of symptoms. It is not a part of normal aging. Dementia is caused by damage to the brain from disease or trauma.

ALZHEIMER'S

Alzheimer's disease is the most common cause of dementia. Other causes include vascular dementia, Lewy body dementia, and frontotemporal dementia. For more information on other forms of dementia, see page 40.

TYPES OF DEMENTIA

Dementia is an umbrella term for loss of memory and other thinking abilities severe enough to interfere with daily life.

- Alzheimer's
- Vascular
- Lewy body
- Frontotemporal
- Other, including Huntington's
- Mixed dementia: Dementia from more than one cause

From the Alzheimer's Association

WONDERING AND WORRIED

You may be wondering:

- Is everything OK?
- Should they be checked by a health care professional?
- What if they won't go to a health care professional?

What could you expect at this stage?

You may notice changes in their memory and thinking, which could affect daily life activities. For example, you may notice they:

- Have difficulty performing more than one task at a time
- Have difficulty solving complex problems or making decisions
- Forget recent events or conversations
- Take longer to perform more difficult mental activities such as using the computer

They are likely concerned as well but may not discuss it. Other friends and family may or may not see or notice any changes.

ACTION STEPS

- [ ] **Contact a health care provider** to obtain a medical assessment
- [ ] **Complete health care and financial planning documents** – a person living with dementia should have an advance directive, also called a "health care directive" or "living will," regarding treatment preferences (an Elder Law Attorney can assist)
- [ ] **Complete a general durable power of attorney document** to appoint an agent to assist with financial and related matters
- [ ] **Complete an estate plan,** which may include legal documents such as a will or a trust that direct the disposition of their estate upon death
- [ ] **Have a family meeting** to discuss what's happening and the necessary next steps

WHAT YOU CAN DO

Learn about normal changes with aging and those that may suggest a need for a medical checkup – review list on page 5

Keep track of changes in memory or behavior – if they don't bring them up, find a quiet time and place to discuss

Ask the person you support to have a complete medical checkup – memory and thinking changes may be caused by something treatable or reversible, and it's best to have a diagnosis

Ask trusted family or friends to encourage a medical checkup if they resist having one

If they are covered by Medicare, ask their health care professional for the Medicare Annual Wellness Visit, which includes cognitive impairment testing – preferably before the visit. You can share a letter or speak with the professional about what you've noticed

Primary care professionals can diagnose dementia - if you aren't comfortable with the current health care provider, consider finding a specialist

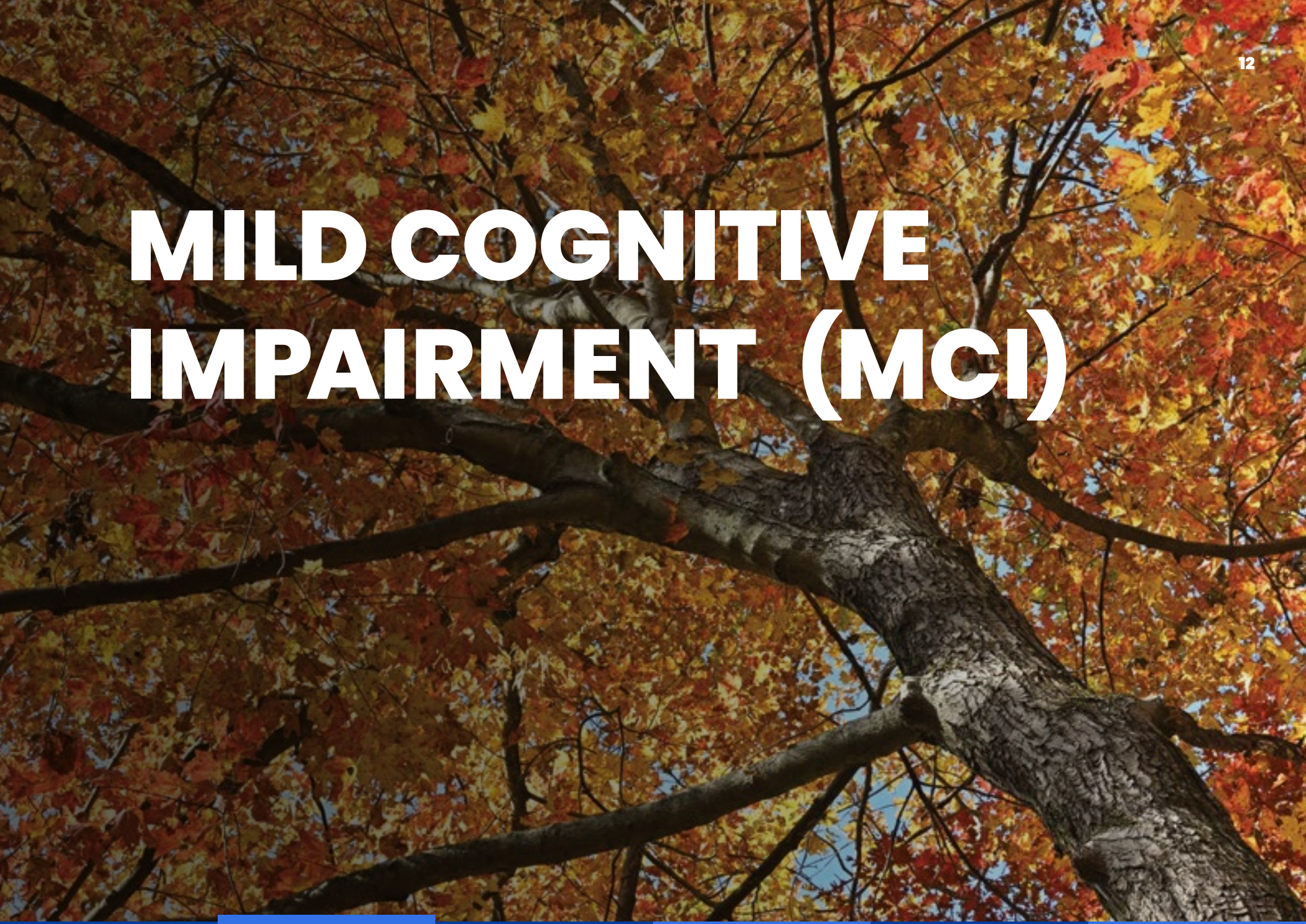
If you think they have hearing loss, get it checked and addressed. Hearing loss can make communication harder and lead to misunderstandings or social isolation

Make sure you and the person you're caring for adopt a healthy lifestyle – eating well and staying active both physically and socially can help reduce your risk of cognitive decline and possibly dementia Learn more

Prioritize completing legal, financial, and advance care planning to protect them against fraud – this is important for all adults, especially those experiencing changes in memory or thinking abilities (see page 39 for resources)

For more advice on working with your doctor or to find a specialist call the Alzheimer's Association at **1-800-272-3900** or **visit their website.**

MILD COGNITIVE IMPAIRMENT (MCI)



MILD COGNITIVE IMPAIRMENT (MCI)

Mild cognitive impairment (MCI) is a slight but measurable decline in cognitive abilities that includes memory and thinking. MCI is not dementia. While a person with MCI is more likely to develop dementia, this may or may not occur.

You may be wondering...

- Where do we go to get memory loss checked out?
- How can I help them with their memory and thinking?
- What can I do to promote their well-being?

What could you expect at this stage?

The person you support:

- Is still independent but may have difficulty paying bills, preparing meals, shopping, and driving
- May forget details, display less ambition, have emotions that change often, and be more reliant on you
- May find success in completing familiar routines and habits

You may:

- Feel irritation with their differing abilities
- Feel compassion for their changes
- Find that other friends and family don't notice changes in the person living with dementia, or understand your concerns

WHAT YOU CAN DO

If they have not yet been evaluated, ask their health care professional for the Medicare Annual Wellness Visit – it includes detection of cognitive impairment along with other screenings

Ask them if you can attend and participate in their medical appointments

Inquire about lifestyle changes that may be helpful to overall wellness and functioning

Learn more about mild cognitive impairment (MCI)

Tell your own health care provider that you are caring for a person with cognitive impairment so they can be aware of your potential health-related risks

Consider keeping a notebook about their changes and needs

Instead of thinking that they should just "try harder," remind yourself that they are doing the best they can

Be generous with your patience

Consider paying bills and shopping together so they can have successes and remain engaged

WHAT YOU CAN DO (CONTINUED)

Support them in managing heart conditions, high blood pressure, or diabetes as needed. For tips, go to www.nia.nih.gov

Encourage a healthy lifestyle including exercise, a healthy diet, and social activities

Encourage the use of skills they have had for many years such as playing the piano, singing, typing, crafting, or speaking a second language

Learn more about how to live well with MCI or Alzheimer's disease – see resources on pages 37-42

CAREGIVER NOTES:

ACTION STEPS

In addition to the action steps on page 10, do the following:

- [ ] If they have not yet had a medical assessment, contact their health care professional, geriatrician, neurologist, or neuropsychologist
- [ ] Discuss with your loved one the issue of when to discontinue driving (see resources on page 38)
- [ ] Encourage family and friends to visit or connect regularly
- [ ] Have a family meeting to discuss what's happening and ways to support the person with memory loss, such as encouraging a checkup with a health care provider, managing medications safely, and/or helping with finances or legal planning

EARLY-STAGE DEMENTIA

EARLY-STAGE DEMENTIA

You may be wondering...

- Are there any medications, treatments, or lifestyle changes that could help their memory and thinking?
- How can I help them stay active and connected?
- Should they still be driving?
- Is their legal paperwork in order?

What could you expect at this stage?

The person living with dementia may:

- Find it hard to accomplish some activities
- Have trouble with time or sequence of events
- Forget names of familiar people and things
- Have decreased performance in work or social situations
- Have trouble multi-tasking
- Take more time to process information
- Write reminders and lose them
- Have increased preferences for familiar things
- Have mild mood and/or personality changes
- Feel sorrow, suspicion, anger, or frustration
- Show increasing indifference to normal courtesies of life
- Have more trouble driving safely

At the same time, you may find that some kinds of memory work quite well. They will likely remember stories from long ago and how to do familiar things, such as playing an instrument. They may focus more on the present moment, enjoy humor, and grow in creativity.

You may:

- Feel optimism and/or an early sense of loss
- Need to give reminders and supervise more
- Want to help around the home such as housekeeping, errands, laundry, or yard work
- Be impressed by their ability to adapt and grow during challenges
- Learn how to redirect their attention

Fayerweather Island Lighthouse
Bridgeport, Connecticut

WHAT YOU CAN DO

Be an advocate for the right diagnosis and best health care – if needed, find a health care professional that will work with both of you

Learn about the disease and how to communicate with them

See "Communication tips" on page 35

Put safety measures in place before they're needed related to falls, wandering, power tools, guns, etc. Find safety resources on page 37

Embrace the good days and prepare yourself for the stormy ones

Make your life a guilt-free zone

Try to get a good night's sleep every night

Get support from others with similar experiences (e.g., early memory loss support group) or call the Alzheimer's Association 24/7 Helpline See page 37

Explore how they want to live at the end of their life (see resource list on page 39 for "Your Conversation Starter Kit")

Keep up your own health and wellness appointments

WHAT YOU CAN DO

When considering care transitions and housing options for someone with Alzheimer's, the primary options include:

- in-home care with assistance
- adult day care centers
- assisted living facilities
- memory care units within assisted living
- and nursing homes

The choice often depends on the stage of the disease and the individual's needs, ranging from minimal support in early stages to around-the-clock medical care in later stages. You should research and select a provider that offers specialized programs tailored to dementia care. Start this process early, as some options can have waiting lists.

CAREGIVER NOTES:

EARLY-STAGE DEMENTIA

To help the person living with dementia:

- Provide *Taking Action—A Personal and Practical Guide for Persons with Mild Cognitive Impairment (MCI) and Early Alzheimer's Disease* found in the resource list on page 38
- Attend medical appointments if they agree; if not, call the health care provider ahead of appointments to share concerns
- Create and stick to simple routines
- Monitor proper medication use
- Help them continue activities that bring joy
- Promote their best health possible by checking things like hearing and vision regularly
- Ensure hearing aids and glasses are in good condition and used as needed
- Resist stepping in to do tasks; allow more time and occasional errors
- Encourage attendance at early-stage support groups and dementia-friendly recreation
- Suggest considering clinical trials or research study enrollment to provide purpose and support treatment development
- Recognize out of character behaviors as part of the disease
- Modify their favorite activities rather than giving them up
- Help family and friends learn communication and interaction strategies, including what they like to do, how to start conversations, and the importance of avoiding correction and arguments

SERVICES TO CONSIDER

- ☐ Educational workshops or care partner classes, offered in person or online by the Alzheimer's Association or local community organizations like senior centers
- ☐ Online tools and communities such as Alzheimer's Navigator, ALZConnected, e-learning modules from the Alzheimer's Association, or the Alzheimer's Reading Room
- ☐ Locator aids with GPS tracking and programs like **Connecticut Bring Me Back Home** (see page 39)
- ☐ Steps to help prevent financial missteps and exploitation, such as removing credit cards, lowering credit limits, or removing other sensitive items from their wallet

ACTION STEPS

In addition to the action steps on pages 10 and 13 do the following:

- [ ] If they are still driving, review the resources on page 38 together
- [ ] Have a family meeting to discuss what's happening and next steps, such as ways the family can support the person with memory loss to stay active, healthy, and socially engaged, or help you with decisions and planning around driving or other safety concerns
- [ ] Make sure they either carry ID or use a geolocator service
- [ ] Make a backup plan to be used if something happens to you
- [ ] Discuss their wishes for end-of-life care and document these as decisions
- [ ] Complete an Advance Directive and General Durable Power of Attorney form
- [ ] Consider a Medical Order for Life-Sustaining Treatment (MOLST) – a medical order completed with your health care provider to honor their wishes for treatment as they move from one health care setting to another (see page 39)

You're not alone. Reach out to resources for support:

Area Agencies on Aging
800-994-9422
www.agingct.org

Alzheimer's Association
800-272-3900
www.alz.org/ct

MID-STAGE DEMENTIA

MID-STAGE DEMENTIA

You may be wondering...

- What can I do to make the house safer?
- What do I do if they won't stop driving?
- Where do I get help coping with behaviors?
- What services might help, and where do I find them?
- How can I make their life more enjoyable?

What could you expect at this stage?

The person living with dementia may:

- Exhibit more obvious confusion
- Have increasing needs for care and supervision
- Have more trouble with memory such as recalling their own address or personal history
- Have problems organizing, planning, following instructions, and solving problems
- Not recognize familiar people
- Forget how to initiate routine tasks or how to complete them, including health and hygiene care
- Resist bathing or other personal care
- Have episodes of incontinence
- Have abilities that vary from one day to the next
- Complain of neglect
- Blame others when things go wrong

MID-STAGE DEMENTIA

The person living with dementia may (Continued):

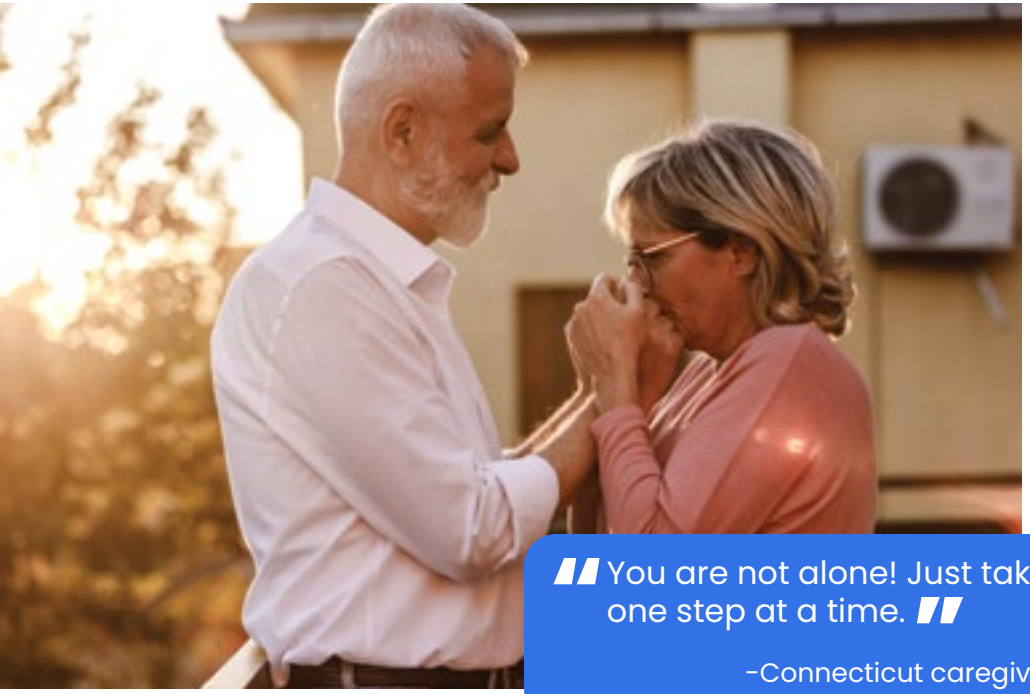
- Lack judgment and develop the following behaviors:
  - Trouble sleeping
  - Displays lack of interest
  - Irritability, aggressive talk and actions
  - Depression
  - Clinging (following you around)
  - Repetitive questions
  - Wandering
  - Delusions (false beliefs) or hallucinations (seeing/hearing things that aren't there)
- Have more problems with balance/falls
- Decreased fine motor skills
- Difficulty with multitasking
- Not be able to contribute to family life in traditional ways
- Be increasingly sensitive to the care partner's mood and behavior

At the same time the person living with dementia may be increasingly present in the moment, continue to use their five senses to enjoy the world around them, discover new ways of communicating (e.g., nonverbal, touch), and be creative.

WHAT YOU CAN DO

You may:

- Feel tired, stressed, lonely, isolated, angry, or irritable
- Be wondering if you need assistance, or how long you can do this
- Notice that other friends and family are wondering how to help, sometimes wanting to take over the care



"You are not alone! Just take one step at a time."

-Connecticut caregiver

Spotlight on sundowning:

Sometimes a person living with dementia will behave in ways that are difficult to understand in the late afternoon or early evening. This behavior can be more apparent in the winter months, with decreased sunlight.

When restlessness, irritability, and confusion happen as daylight begins to fade, it's known as 'sundowning.' While many are aware of the memory decline associated with Alzheimer's disease and related dementia, changes in the brain will eventually affect all five senses, including sight. These changes in visual perception can increase disorientation in dark or shadowy environments, both indoors and outdoors.

To help prevent and mitigate sundowning:

- Ensure adequate sleep
- Stick to a schedule
- Get daily sunshine by going outside or sitting near a window
- Aim to be physically active each day but don't plan too many activities
- Avoid alcohol and caffeine late in the day
- Discourage long naps and dozing late in the day
- Turn lights on earlier
- Limit shadows late at night by covering windows or screens that aren't in use

For more tips, visit National Institute on Aging or Alzheimer's Association, page 37.

WHAT YOU CAN DO

At this stage, you will need the following kinds of support:

Take regular breaks from caregiving tasks (known as respite)

Build a network of caring friends, family, and other care partners

Prioritize time for your own self-care

Establish or maintain routines for you and your person living with dementia

Practice patience with mood changes and emotional shifts

Recognize that behavior is a form of communication

Set emotional boundaries to avoid taking behaviors personally

Ask for help with home tasks or caregiving responsibilities

Attend a support group

Vent as needed with trusted friends or other care partners

Take safety precautions to prevent falls, wandering, medication misuse, and household hazards (e.g., cleaning products, stove, knives, firearms, power tools)

Seek support in addressing their unsafe driving (with help from their health care provider or the Alzheimer's Association)

Explore support and service options to help maintain their current living arrangements, in-home care, and adult day services. There are respite programs that can pay for these services that can be found at portal.ct.gov

Learn about residential care options, including costs, locations, and availability. These might include assisted living or nursing homes. Take tours to prepare for quick decision making

If you get unwanted opinions or criticisms, recognize that others may be trying to help. Try to work out a plan for them to assist in some way. Remember, you are doing the best you can

CAREGIVER NOTES:

MID-STAGE DEMENTIA

To help the person living with dementia:

- Encourage family and close friends to learn communication tips and techniques and provide meaningful activities
- Refer them to the Alzheimer's Association website (www.alz.org/ct) or 24/7 Helpline: **800-272-3900**
- Show kindness, understanding, and acceptance
- Offer purposeful activities like walking, gardening, or simple house activities like folding laundry to maintain their sense of purpose
- Simplify tasks and break activities into smaller steps
- Listen to familiar music, look at old photo albums, a memory book, or old videos
- Ensure they receive ongoing medical care
- Contact their physician if you notice sudden behavior changes – this can be a sign of an infection or other medical issue
- Ask their doctor about a Medical Order for Life-Sustaining Treatment (MOLST) form and ask for a referral to a physical or occupational therapist for a home safety evaluation
- Explore the Alzheimer's Association Caregiver Center (www.alz.org/care) for tips on daily care and home safety

SERVICES TO CONSIDER

- [ ] Education workshops or conferences for care partners
- [ ] Technology to assist with a variety of tasks (e.g., medication reminders, cameras, door alarm)
- [ ] Adult day services that offer the person living with dementia activities, exercise, socialization, medical supervision, and provide you with some time for yourself
- [ ] In-home care to assist with bathing, dressing, getting ready, other personal care tasks, and routines
- [ ] Counseling to handle grief, depression, anger, and to get emotional support
- [ ] Support groups
- [ ] Respite care (in or out of the home)
- [ ] Specialists trained in caregiving issues and behaviors
- [ ] GPS locator program

Residential care options:

In addition to services that can help a person with dementia stay at home, there are many different types of homes or facilities that provide long-term care. Counseling services are available to help you explore your options, understand what is available, and make informed decisions based on your unique situation. Residential care options in Connecticut include assisted living, residential care facilities, and nursing homes.

To find out more about what's available in your area, go to your local Alzheimer's Association at **800-272-3900** or www.alz.org/ct, the Area Agencies on Aging at **800-994-9422**, dial **2-1-1** or visit 211ct.org.

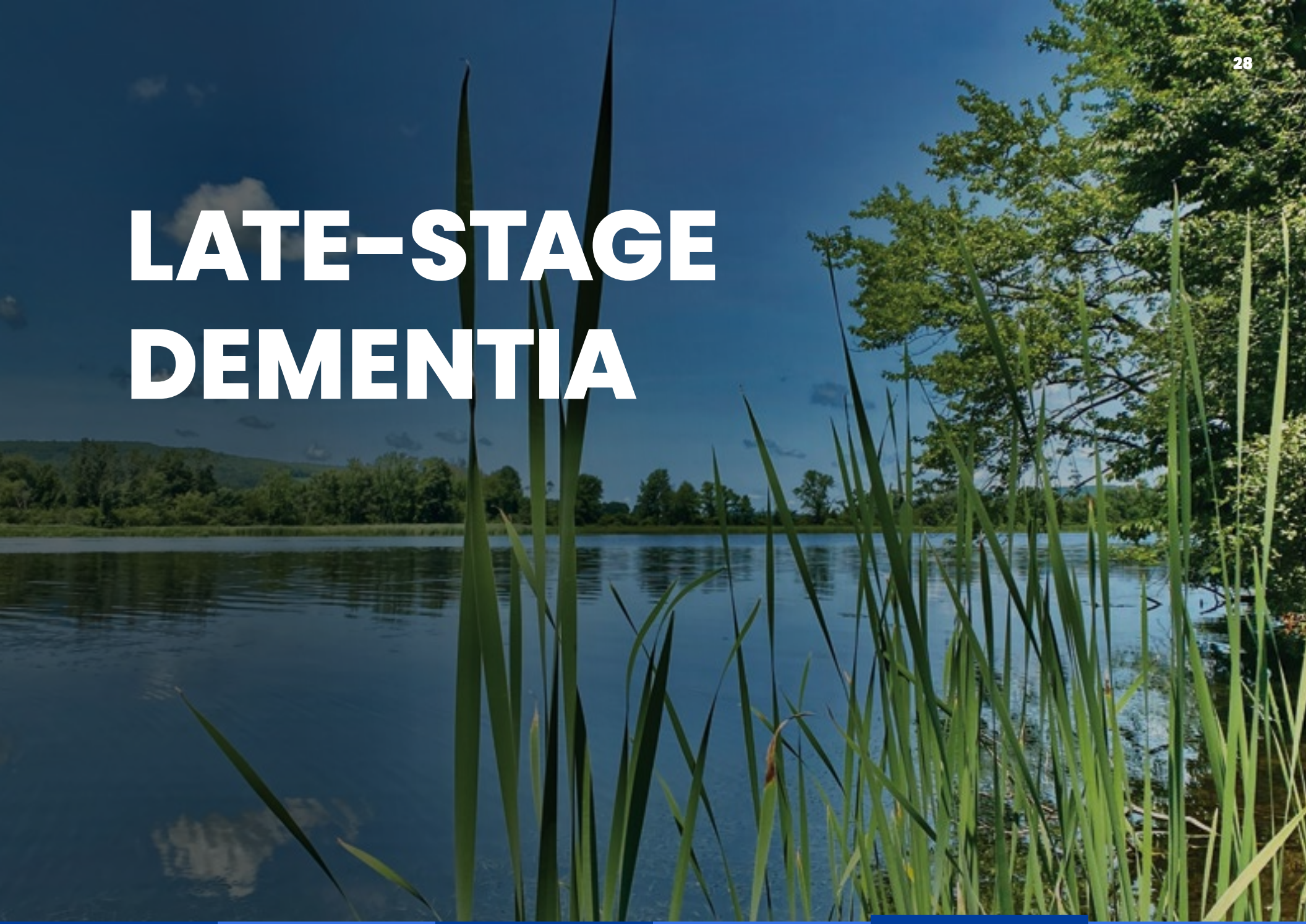
> "The person living with dementia is not **GIVING** you a hard time, they are **HAVING** a hard time."
>
> -Connecticut caregiver

ACTION STEPS

In addition to the action steps on pages 10, 13 and 20, do the following:

- [ ] Request a home safety evaluation with a physical or occupational therapist to make the home safer and home care tasks easier
- [ ] Have a family meeting to discuss what's happening now and explore ways to support them and you, including next steps as care needs increase
- [ ] Update your backup plan in case something happens to you
- [ ] If help with financing care is needed, the Area Agencies on Aging and the Alzheimer's Association can help you explore options
- [ ] Complete end-of-life planning – discuss and document how your loved one wants to live at the end of their life, including medical care wanted or not wanted, comfort measures, palliative, and hospice care

LATE-STAGE DEMENTIA



LATE-STAGE DEMENTIA

You may be wondering...

- What can I do to promote a quality life?
- What kind of care is best for them?
- What medical care will support their comfort and values at the end of their life? This may include options like palliative or hospice care.

What could you expect at this stage?

In the late stage, they are completely dependent on others for personal care activities.

They may:

- Not recognize you or others (though they may still know or feel who you are)
- Have increasing difficulty communicating, including "word salad" or loss of speech
- Rely more on nonverbal communication such as pointing, refusing to move, or turning away
- Be frequently or totally incontinent
- Experience physical changes in walking, sitting, or swallowing
- Have rigidity, immobility, jerks, or seizures
- Express deep emotions through screaming, swearing, moaning, flailing, or hitting
- Use body language to express pain
- Be vulnerable to infections, especially pneumonia or urinary tract infections

At the same time, you may notice they are still attuned to the emotions of others, enjoy companionship, respond to physical touch or music, and can encourage others to slow down and focus on the present.

You may:

- Acknowledge the love and support you've given
- Continue caring for your own well-being
- Allow extra time for tasks and activities
- Share quiet moments that don't require words
- Actively seek palliative or hospice care
- Review health conditions and medications with a care provider
- Consider emotional support during and after end-of-life experience
- Attend a support group or counseling
- Include close friends and family in end-of-life discussions and planning
- Be gentle with yourself and them

WHAT YOU CAN DO

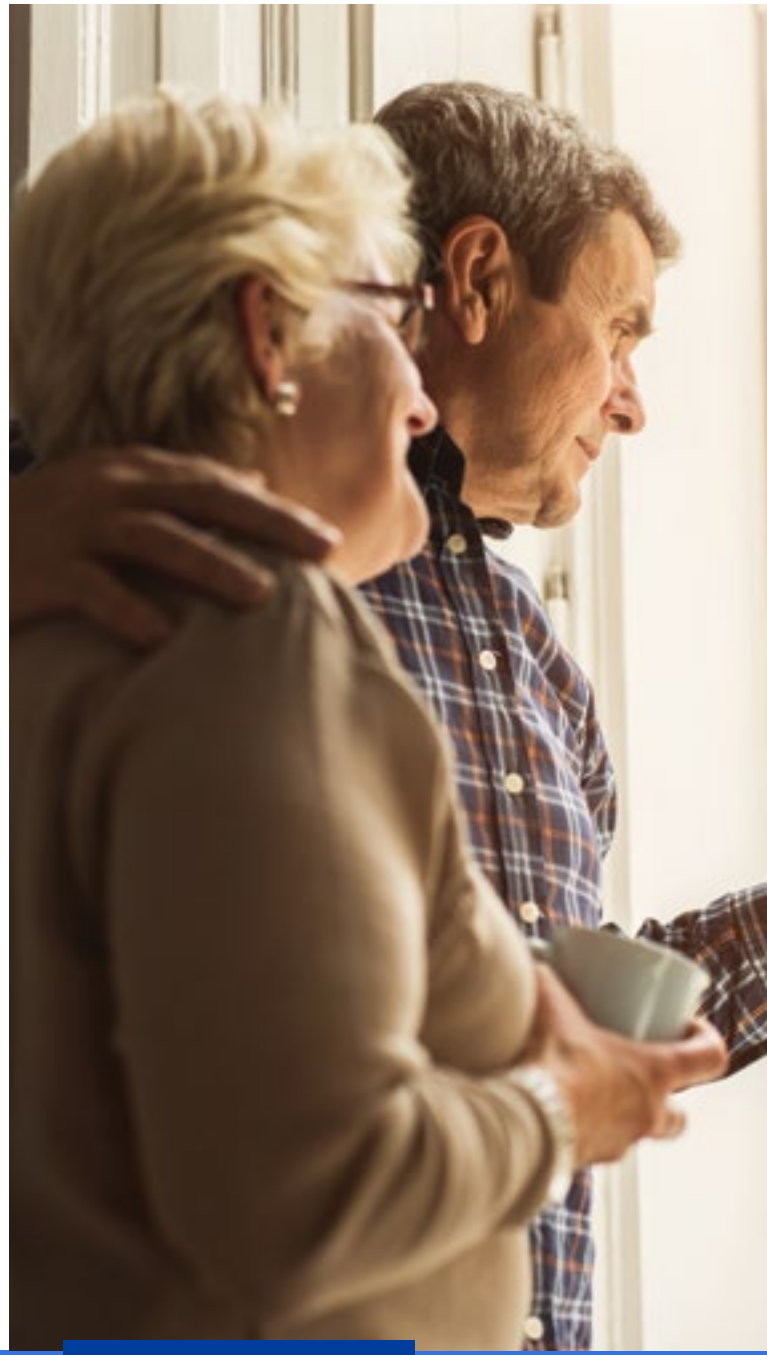
Should you consider palliative or hospice care?

Palliative and hospice care are holistic approaches that can improve quality of life, reduce risk of depression, and support a greater sense of independence. These programs provide families and caregivers with more support in facing a serious illness like Alzheimer's disease. Although these services are often covered by private insurance, Medicare, and Medicaid, they are underutilized due to misconceptions, lack of awareness, and late referrals.

Palliative Care: Medical care that provides individuals relief from the symptoms, conditions, and pain that accompany a chronic disease or illness. This care can be used at any stage of the illness.

Hospice Care: Specialized type of palliative care for individuals who have a terminal illness with a life expectancy of six months or less. Hospice care focuses on controlling and alleviating pain and other symptoms of illness so the individual can be comfortable near the end of life. The person and/or family will agree not to have curative or life-prolonging interventions.

Palliative and hospice care are delivered by a multi-disciplinary team of physicians, social workers, nurses, and spiritual advisors. Hospice care can be provided in the home, hospital, long-term care facility, or hospice facility.



WHAT YOU CAN DO

To help the person living with dementia:

- Maintain simple routines with a mix of rest and activity
- Spend time outdoors for fresh air (e.g., walking or sitting on porches)
- Recall meaningful life events using photos or videos
- Play or sing music they enjoy
- Appeal to the senses with things like fresh orange juice, flowers, or scented lotions
- Encourage regular visits from family and friends
- Offer kind words, loving hugs, and other comforting gestures, even if they are no longer verbal or mobile

You may feel like this:

"I'm worn out, and I am grieving."

-Connecticut caregiver

LATE-STAGE DEMENTIA

CAREGIVER NOTES:

SERVICES TO CONSIDER

- [ ] In-home or residential care
- [ ] Palliative and hospice care
- [ ] Support groups
- [ ] Counseling or other emotional support for yourself

ACTION STEPS

In addition to the action steps on pages 10, 13, 20 and 27, do the following:

- [ ] Discuss and plan for palliative and hospice care with their health care provider

Find support from others in a similar situation, a care coordinator, a counselor, and/or contact:

Alzheimer's Association
800-272-3900
www.alz.org/ct

Area Agencies on Aging
800-994-9422
www.agingct.org

SUMMARY: COMMON PROGRESSION OF DEMENTIA SYMPTOMS

Early–Stage Dementia:

- Trouble with time or sequence of events
- Forgetting names of familiar people and things
- Decreased performance in work or social situations
- Trouble multi-tasking
- Taking more time to process information
- Increased preferences for familiar things
- Mild mood and/or personality changes
- Feeling sorrow, suspicion, anger, or frustration
- Less concern for manners or polite social behavior
- Trouble driving safely

Mid–Stage Dementia:

- Increasing needs for care and supervision
- More trouble with memory, such as forgetting their address or personal history
- Difficulty organizing, planning, following instructions, or solving problems
- Not recognizing familiar people
- Forgetting how to start or complete tasks, including health and hygiene care
- Possible resistance to bathing or other personal care
- Abilities that vary from day-to-day
- Complaints of neglect or blaming others when things go wrong
- Poor judgment and behaviors such as trouble sleeping, apathy, passivity, irritability, aggression, clinging (e.g., following you around), repetitive questions, and wandering
- Delusions (false beliefs) or hallucinations (seeing or hearing things that aren't there)
- Balance issues, increasing the risk for falls
- Inability to contribute to family life in traditional ways

Late–Stage Dementia:

- Dependence on others for personal care
- Not recognizing you or others (though they may still sense who you are)
- Changes in physical abilities, including walking, sitting, and eventually swallowing
- Increasing difficulty communicating, including word salad (mixed-up words) or loss of speech (nonverbal communication may work best)
- Frequent or complete incontinence
- Rigidity, immobility, jerks, or seizures
- Strong emotional reactions, including screaming, moaning, or flailing
- Increased vulnerability to infections, especially pneumonia and urinary tract infections

GUIDANCE

COMMUNICATION TIPS

Dementia damages pathways in the brain. Changes to the brain can make it difficult for a person with dementia to express what they want and understand what others are saying. A person living with dementia may struggle to come up with the right words or a name, or they may invent new words. At some point, they might begin repeating the same question multiple times.

Since dementia gradually affects communication skills, their words may sometimes make little or no sense to you. They may also have trouble understanding what you say. These misunderstandings can fray nerves, making communication even more difficult.

Over time, a person living with dementia may struggle to organize their thoughts, lose their train of thought, or speak less often.

WHAT YOU CAN DO

Be present.
Let them know you're listening and trying to understand. Keep your voice gentle. Hold the person's hand while you talk. Smile, nod, and make eye contact when appropriate.

Show respect.
Offer them undivided attention by not multi-tasking. Include them in conversations; don't talk about them as if they aren't there.

Avoid distractions.
Background noise, such as from TVs or radios, can compete for attention.

Position yourself.
Be close enough to be heard and seen clearly. Sit or stand at the same level, rather than standing over them.

Get their hearing checked regularly.
If the person uses a hearing aid, check that it is working and inserted properly. When speaking, turn your face toward them and make sure it's well-lit so they can easily see your lip movements.

Keep it simple.
Use short sentences. Ask one question or offer one instruction at a time. It usually helps to use positive language. For example, say "Let's go here" vs. "Don't go there." As the disease progresses, ask questions that can be answered with a yes or no.

Allow time and be patient.
Slow your speech slightly and allow time for the person to process and respond. Try to avoid interrupting. If you're feeling rushed or stressed, take a moment to calm down.

Focus on feelings.
Listen for the meaning behind the words. Their tone or body language may provide clues. Respond to the emotions.

Offer comfort.
If a person with dementia is having trouble communicating, let them know it's okay. Offer hugs or hold their hand if appropriate.

COMMUNICATION TIPS

Use visual cues.
Gestures or other visual cues can help promote better understanding than words alone. Rather than asking if they need to use the toilet, walk them to the toilet, and point to it. Demonstrate a task first.

Watch your tone and manner.
Try to keep your voice soft and gentle. No one likes to be talked down to or criticized. Try not to sound bossy. Use friendly facial expressions and non verbal cues that convey calm. A person with dementia responds to others' moods; if you're upset, they may become upset too.

Avoid quizzing and arguing.
Instead of questioning or correcting, listen for the meaning of what they're saying. Try to avoid arguing — no one will win, and it will only lead to embarrassment, frustration, or anger.

It's important to remember that they aren't trying to be difficult.
The disease has changed their brain. Try your best not to take communication and behavior personally.

It's also important to know that these are offered as suggestions. We encourage you to forgive yourself when things don't go the way you want. It can be helpful to talk with others in the same situation to get more ideas and support.

> **"I realized it is much easier for me to enter her world than for her to live in mine."**
>
> -Connecticut caregiver

DEMENTIA RESOURCES

CT State Plan/Department of Public Health
For information on brain health, ADRD, and the CT State ADRD Plan.

Connecticut State Department of Aging and Disability
Support can include counseling, support groups, caregiver training, and respite care to allow caregivers to take breaks.

Area Agencies on Aging
They are a trusted source of information and assistance, where older adults can turn to find specialized information, support, and service options in their area: respite programs, in-home care, Medicare counseling, healthy aging programs, and more.
800-994-9422

Alzheimer's Association Connecticut Chapter
They have a 24/7 helpline that provides expert advice, care consultation, and referrals at both national and local levels. They also offer assistance with training, support groups, prevention, diagnosis, and treatment.
800-272-3900

United Way of Connecticut 211
211 is a free, confidential information and referral service that connects people to essential health and human services 24/7/365 online and over the phone. 211's contact specialists can connect you to information about memory care facilities, assistive devices, support groups for caregivers and how to protect yourself from fraud and scams.
2-1-1

10 Healthy Habits for your Brain

Diagnostic Tools

Treatments for Alzheimer's Disease

Information on Prevention Research

CAREGIVER RESOURCES

Alzheimer's Caregiving

Dementia and Driving
Information on signs of unsafe driving, concerns and more.

Unsafe Driver Affidavit
If you are concerned that your loved one should not be driving anymore, you can submit an affidavit to the Connecticut Department of Motor Vehicles to take action.

The Alzheimer's Foundation of America- The Apartment - A Guide to Creating a Dementia-Friendly Home

Caregiver Action Network (CAN)
Serves a broad spectrum of family caregivers, including those caring for people with Alzheimer's disease and related dementias. Free resources including "Kindly Human" peer to peer support.

I Have Alzheimer's

Living Well:
A Guide for Persons with Mild Cognitive Impairment & Early Dementia.

Taking Action
A Personal and Practical Guide for Persons with Mild Cognitive Impairment (MCI) and Early Alzheimer's Disease.

Dementia Self-Management Guidebook
DEER The Dementia Engagement, Education, and Research Program. If you have been diagnosed with a dementia-related condition, then it is important to know: you can live well with dementia. This Dementia Self-Management Guidebook, based on the science of chronic disease self-management, was developed in partnership with six advisors who are living well with dementia.

LEGAL AND ADVANCE CARE PLANNING

Your Conversation Starter Kit

For families and loved ones of people with Alzheimer's disease or other forms of dementia. It is designed to be used in the early stages of dementia.

Bring Me Back Home

A confidential and secure registry for Connecticut residents which allows law enforcement personnel access to information to assist in the recovery of missing or wandering persons with cognitive impairment such as Alzheimer's in an emergency.

Medical Orders for Life Sustaining Treatment (MOLST)

MOLST is a medical order form (similar to a prescription) that relays instructions between health professionals about a patient's care. MOLST is based on an individual's right to accept or refuse medical treatment, including treatments that might extend life. MOLST is not for everyone. In Connecticut, patients approaching the end stage of a life limiting illness or in a condition of advanced progressive frailty may discuss filling out a MOLST order with their clinician. The patient's decision to use the MOLST form is and must always be voluntary. MOLST is different from a health care representative form. It is recommended that all adults aged 18 and older complete a health care representative form to name the person who can make medical decisions for them in the future event of an unexpected illness or accident. It is also suggested that anyone with a MOLST form also fill out the health care representative form.

RESOURCES ON OTHER DEMENTIAS

Alzheimer's Association, Types of Dementia

The Association for Frontotemporal Degeneration

Lewy Body Dementia Association

CAREGIVER NOTES:

ACTION STEPS SUMMARY

- [ ] **Contact the Alzheimer's Association Connecticut Chapter.** They have a 24/7 helpline that provides expert advice, care consultation, and referrals at both national and local levels. They also offer assistance with training, support groups, prevention, diagnosis, and treatment.
www.alz.org/ct
800-272-3900

- [ ] **Contact the Area Agencies on Aging.** They are a trusted source of information and assistance, where older adults can turn to find specialized information, support, and service options in their area: respite programs, in-home care, Medicare counseling, healthy aging programs, and more.
www.agingct.org
800-994-9422

- [ ] **United Way of Connecticut 211**
211 is a free, confidential information and referral service that connects people to essential health and human services 24/7/365 online and over the phone. 211's contact specialists can connect you to information about memory care facilities, assistive devices, support groups for caregivers and how to protect yourself from fraud and scams.
www.211ct.org
2-1-1

- [ ] **Complete a General Durable Power of Attorney.** Complete an estate plan and a health care planning document as part of your concerned person's documents. They should have an estate plan that may include legal documents, such as a will or a trust, that direct the disposition of their estate upon death.

ACTION STEPS SUMMARY

- [ ] **Obtain a medical assessment of memory loss or cognitive impairment and diagnosis for your concerned person.** This opens the door to necessary planning. The process should start with your health care practitioner and may involve other specialists such as a geriatrician, a neurologist, and/or neuropsychologist.

- [ ] **Complete health care planning documents.** The person with dementia should have an Advance Directive (also called a "health care directive" or "living will") regarding treatment preferences.

- [ ] **Discuss with them the issue of when to discontinue driving.** If needed, enlist a health care provider's help or get a professional driving evaluation. You can also call the Alzheimer's Association for more ideas.

- [ ] **Make sure the person either carries ID or uses a geolocator service,** such as their cell phone service, to be located electronically. Also ensure the police and fire department are notified in case they go missing.

Mystic Seaport Light
Mystic, Connecticut

ACTION STEPS SUMMARY

- [ ] **Have family meetings** along the way to discuss what's happening, and how to support the person with memory loss and their care partner. Important topics of discussion include:
  - Encouraging a diagnosis
  - Discussing safety issues, such as driving and safe medication use
  - Needing support with financial or legal planning
  - Coordinating care at home
  - Considering safe living situations and options
  - Supporting the primary caregiver or care partner
- [ ] If you need help with financing care, **contact the Area Agencies on Aging for options.**
- [ ] **Request a home safety evaluation** with a physical or occupational therapist to make the home safer and home care tasks easier
- [ ] **Make and update a backup plan** along the way in case something happens to you
- [ ] **Discuss and seek** palliative and hospice care

This guide was created by the Connecticut Department of Public Health (DPH) and the Connecticut Department of Aging and Disability Services (ADS) as part of an effort by the Connecticut ADRD Coalition, a committed group of professionals and volunteers from all over CT. This guide was adapted with permission from the original Washington Dementia Roadmap and Oregon Dementia Roadmap to fit the needs of Connecticut residents. Many thanks to our colleagues from the west!

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